Professor Mark Walport, registrar of the academy, accepted that the importance of consent related to the potential level of harm that could result from either the procedure or the sharing of data. With this in mind, surely, the use of anonymised data could not result in any harm to the individual, and, consent therefore need not be given? Baroness O'Neill agreed with the conclusion, but said that the best way forward was to make clear from the outset the purposes or actions for which the patient was giving informed consent, including the secondary use of data. But it seemed absurd to insist on specific informed consent for the use of anonymised data. Firstly, it would be unfeasible as many data are old and secondly, because so many people can benefit from the use of such data. With proper safeguards, generic consent should cover the anonymous use of data in subsequent studies.

Professor Julian Peto from the Institute of Cancer Research pointed out that anonymisation of the data does not mean no one knows to which patient the data refers. Indeed, when using old data—for example, for comparing rates of breast cancer and abortion, named data have to be used. Baroness O'Neill pointed out that anonymisation did not mean nobody knew the identity of patients, just that they were not published. She advised that, at some stage well before publication, data should be coded.

REFERENCES

1 **Faden R**, Beauchamp T. *A history and theory of informed consent*. New York: Oxford University Press, 1986.
2 **Rothman D**. *Strangers at the bedside: a history of how law and ethics transformed medical decision making*. New York: Basic Books, 1991.
3 **Wolpe P**. The triumph of autonomy in American bioethics: a sociological view. In: Devries R, Subedi J, eds. *Bioethics and society: sociological investigations of the enterprise of bioethics*. Englewood Cliff, NJ: Prentice Hall, 1998: 38–59.
4 **Mill JS**. On liberty. In: Warnock M, ed. *Utilitarianism, On Liberty and other essays*. London: Fontana, 1962: 135.
5 **Jenkins S**. A sad case of media meddling not reason. *The Times* 2000 Feb 8.
6 **Dworkin G**. *The theory and practice of autonomy*. Cambridge: Cambridge University Press, 1988: 6.
7 **See reference 1: 8**.
8 **O'Neill O**. *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press, 2002.
9 **Nuffield Council on Bioethics**. *Human tissue: ethical and legal issues*. London: Nuffield Council on Bioethics, 1995. http://www.nuffield.org.uk/bioethics/index.html. O'Neill O. Medical and scientific uses of human tissues. *Journal of Medical Ethics* 1996;**22**:1–3.
10 **House of Lords' Select Committee on Science and Technology**. *Report on human genetic databases: challenges and opportunities*. HL57; written evidence, 2000, HL 115. http://www.parliament.the-stationery-office.co.uk/pa/ld/ldsctech.htm
11 *The report of The Royal Liverpool Children's Inquiry*. London: The Stationery Office, 2001: http://www.rlcinquiry.org.uk/

ECHO

Informed choice and screening organisation

Please visit the Journal of Medical Ethics website (www.jmedethics.com) for link to this full article

Patients are more likely to make an informed choice to accept a screening test if it is arranged as part of a routine hospital visit rather than if it requires a separate visit. As the rate of informed choice is influenced both by the information provided and the manner in which testing is organised, it is essential to discover the method of organisation that leads to the highest rate of informed choice. Two general hospitals were compared, each applying a different method of organisation for maternal serum screening for Down's Syndrome. One hospital offered the test as an extension of the routine blood taking visit whilst the other arranged for a separate visit to take place especially for the test.

A questionnaire that measured knowledge of the test and attitudes towards it was returned on time by 84% of the 2313 eligible women. The results were measured against eventual uptake and showed that the proportion of women making an informed choice to accept the test was higher at the routine visit hospital than the separate visit hospital (41% v 21%). A similar proportion at both hospitals (23%) made an informed choice to decline the test.

Whether choice is informed or not is more important in some screening programmes than the level of uptake - particularly in prenatal programmes where the potential outcome can lead to invasive tests or termination. The authors therefore recommend that a randomised trial is undertaken to determine whether or not the causal findings from this descriptive study stand up to critical appraisal.

▲ *J Med Screen* 2002;**9**:109–114.